

State of the Art of RD Activities in Europe Resource (SotAR): Survey Technical Guidance

Thank you for completing this survey: your contributions are greatly appreciated. The survey tool is simple to use and intuitive. This guidance document aims to escort you through the process of answering the survey questions and steer you through any problems which may arise.

If you work your way through the guidance notes and still cannot resolve your query please contact victoria.hedley@ncl.ac.uk

Completing the questionnaire

The link to your survey is sent to all Data Contributing Committee (DCC) members simultaneously. It is important that each DCC agrees how they would prefer to complete the questionnaire/ review their previously submitted data.

- Some DCCs may prefer to allow the Competent National Authority (e.g. Ministry of Health) representative to complete as much as they can initially, using the information they already have available in their role. In this case the other DCC members would be expected to *review* this information and make additions where relevant.
- However, you may prefer in your DCC to allocate certain sections of the survey to specific members of the DCC to complete/update in the first instance, as opposed to waiting for the Competent National Authority representative to complete all sections independently.
- If helpful, you can ask the Newcastle team to arrange a conference call to discuss who will 'address' each section first, or indeed a little further down the line, to discuss any areas of uncertainty prior to the final submission.

Tip: The survey link seems to work better in Google Chrome than Internet Explorer.

Upon entering the survey using the link provided via email by the UNEW team, you will see that each screen from Section 1 onwards will display three buttons at the bottom of the page: e.g.

State of the Art for RD Copy

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Section 4: Neonatal Screening

* Please summarise policies and legislation pertaining to newborn/neonatal screening in your country.

* How many rare diseases are covered in the neonatal screening programme in your country? (Please list)

Resume later Previous Next

Question index

1. Section A: Identification
2. Section 1: National Plans and Strategies f...
3. Section 2: Rare Disease Registration
4. Section 3: Definition of a Rare Disease
5. Section 4: Neonatal Screening
6. Section 6: Centres of Expertise
7. Section 7: European Reference Networks...
8. Section 8: National Alliance of Patient Or...
9. Section 9: National Helplines for Rare Dis...
10. Section 10: Activities of Orphanet/Altern...
11. Section 11: Official Information Centres...
12. Section 12: Clinical Practice Guidelines (...)
13. Section 13: Training and Education
14. Section 14: Rare Disease Events
15. Section 15: Existence of RD research pr...
16. Section 16: Participation in E-Rare and I...
17. Section 17: Orphan Medicinal Products (...)
18. Section 18: Social Services and Social I...
19. Section 19: Other

'Previous' and 'Next' (the middle buttons) are self-explanatory: pressing these buttons will allow users to navigate to the previous and subsequent sections of the questionnaire.

Remember to save your responses at regular intervals by pressing 'Resume Later' in the bottom left corner.

Whenever you wish to exit the survey simply save your responses by clicking 'Resume Later' and then close the browser window at the top of your screen (there is no dedicated exit button).

As well as using 'Previous' or 'Next' buttons you can skip to any section of the questionnaire you wish using the Questionnaire Index on the right-hand side of the screen. This is particularly useful if your DCC has dedicated to allocate certain sections for completion by different members in the first instance. Using this question index also means that you can begin to complete a later section, say section 10, even before the earlier sections have been completed. The Sections appear exactly as per the PDF Question Bank document you have been issued.

Submission Stage

When you get to the final section of the survey a '**Submit**' button will appear at the bottom of the screen.

State of the Art of Rare Disease - Activities in EU Member States and Other European Countries

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Section 19: Other

- Please provide details of any other RD related achievements in your country since the beginning of 2014.

- Please summarise what you see as the main areas of improvement/major successes relating to rare diseases since the beginning of 2014.

Resume later

This should be only be pressed once all members of the DCC agree that the information is complete and accurate as possible. If you find, after submission, there is additional data which should have been included please email the information separately to Victoria.hedley@ncl.ac.uk